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Telling it like it is: families living on a low income with deaf children

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Introduction

The project aimed to discover what factors lead to prospects of the deaf child's fluency with language and communication for families on low incomes bringing up deaf children. We wanted to explore whether there are any factors which are crucial for progress, and what parents' views were on which factors they think have led to the most success. The project aimed to find out what access the families had to information and support from their family, their community, and third sector and statutory agencies such as Education and Health. In addition, we wanted to find out what the families saw as the challenges and supports in relation to their deaf child's language and communication development.

The research was funded by the National Deaf Children's Society (NDCS). Their caseworkers had reported that families from a low income background sometimes struggled to access the information and support they need to effectively support their deaf child's development in language and communication.

This project is an important one, because results from previous research have shown that it is deaf children from the poorest backgrounds who have the lowest educational outcomes (O'Neill, Arendt & Marschark, 2014). Access to information and ability to make timely decisions are crucial in affecting outcomes in relation to the success of one or more languages (Ching et al., 2017). Learning to interact with a deaf child is difficult, to keep talking or to start signing and continue to learn more British Sign Language (BSL). These are demanding early years for any family, but particularly for families living on a low income. Families living in poverty often make decisions in very different ways than families with more economic and social capital (Sheehy-Skeffington & Rea, 2017); their rational choices may look irrational to professionals who have no personal knowledge of living on a low income. Indeed, relationships with teachers of deaf children and speech and language therapists who visit the family home regularly from birth was an area explored in this study.



Evidence and analysis

The research was carried out from the Scottish Sensory Centre over 2018. The first part of the study was a literature review of 59 sources, mostly peer-reviewed articles, about families living on a low income bringing up deaf children, with a particular focus on language development. This is an area which has not previously been systematically examined.

The review supported the development of questions for the interview schedule. To be eligible for interview, the family had to be living on a means tested benefit, or their children were eligible for Free School Meals. Families had a deaf child of 12 or under so that it was possible to discuss recent experiences of language learning and choices, and so that all the children deaf from birth should have experienced newborn hearing screening. Families were contacted through local authorities, school services for deaf children, networks of teachers, social workers and other professionals, and third sector organisations such as NDCS and via the project Facebook site. Twenty-one interviews with families were conducted in all parts of the UK.

The 21 families represented a wide range of experience. Twelve were single parents. Seven of the families had 4 or more children and the group had 34 deaf children between them. In 6 of the families there were other spoken languages apart from English, and in 4 households there were deaf parents who mainly used BSL. Six were from minority ethnic groups. Spoken language was the main mode used by deaf children in 13 of the households; however, some level of BSL or sign was used in 16 of the 21 households. These families often chose a mixed language approach in communication with their deaf child in different situations.

The main interviewer, Jo Bowie, had personal experience of bringing up a deaf child whilst living on a low income, which encouraged the parents to talk openly, or as the project was called on the website 'Telling It Like It Is'. The research team included two deaf researchers who interviewed in BSL, and the team also worked with other spoken language interpreters for some interviews. The interviews were transcribed and three members of the research team identified themes from the data, working together to compare findings. This analysis was initially based on the themes from the literature review, adjusted through repeated reading and analysis as new themes emerged.



Picture courtesy of NDCS

Our Findings

Finding 1: Information and Support were often not available.

Many families living on a low income are not receiving as much discussion and support as they need around language and communication choices and equipment in the early years. This was particularly true for parents with weak reading skills and where English was not the main spoken language in the home. Parent confidence was often related to having good information and an alternative source of information such as someone who knows about the education system. The families we interviewed often did not have alternative sources of help and advice.

A hearing parent with very little English, turned to her doctor for advice on literacy because he explained in Punjabi:

The doctor's said to us that if we maybe place two fingers on his neck...or on his throat he will try to make a noise. So we do try that now and then when he's reading. We put that there and he's trying to read it out loud. ... And you know this, it does help now and then.

Leah

Some parents had, however, developed expert knowledge because of persistence and confidence to find out more:

Well I, I went in and I've always been quite open wi' (name of audiologist) and that and asking questions. And like I can read the charts now, like it says it's like Sandra's like 80% whereas she should be at 20 for a normal hearing child and she's hanging at 80, well between 80 and 90. And with her hearing aid she hears probably, she hears just within the speech bubble. So... I sorta like clued myself up and I was always asking questions, asking about the cochlear implant and things like that to see if that would be more beneficial for her... But aye, I've always like been open and asked loads a' questions.

Sara

The literature review revealed that knowledge of the language acquisition process in deaf children can be passed on to parents. Fluency in one or more languages is a pre-requisite for educational progress and is an organisational task which can be tackled in relation to both spoken languages and BSL, but it needs to be approached in culturally appropriate ways with low-income families.

Finding 2: Early diagnosis and engagement with health and education services were often not working well.

From the literature, the targets of screening by 1 month, diagnosis and aiding by 3 months, and starting regular support with the family by 6 months (Yoshinaga-Itano et al., 2017) offer the best chance for better language outcomes for deaf children from low-income backgrounds. From our interviews, it is apparent that newborn screening and early intervention is not proving very effective for many families on a low income. Deaf children from families on a low income were more likely to experience delays in starting aiding and intervention. Families did not have a way of independently offering feedback to professionals until matters came to a crisis, when it was often expressed very dramatically (i.e. by moving or insisting on a different professional). Parents living on a low income have a wide range of skills and strengths, which are not necessarily recognised by the professionals they meet.

One parent had investigated early intervention thoroughly and decided on auditory verbal therapy (AVT) when her daughter was a few months old. She was aware of the importance of speed in making an early start on speech and language therapy. This was not offered to her as a choice; her family raised the money for the monthly trips to Oxfordshire for this therapy by drawing on community resources.

I had researched online and, you know, discovered that with cochlear implants there was a good chance that she could be completely spoken ... And, as I say, with all the research we've done, we discovered, I'd spoken to AVTherapy about two months after she was diagnosed.

Sue

Another parent found teachers of deaf children were positively threatening:

We were living in (name of County) at the time, which is very oral, so the teacher of the deaf came around and told us to not sign at all with her, and that we should do a running commentary as we were walking round the house. If I'm walking into the lounge and I'm turning on the light, and I was going, she can't hear any sound at all, even with hearing aids, like [laughs]...yeah, they were crazy, so we asked for a different teacher of the deaf, cause she refused to help us to learn to sign and suggested, when I was saying I was really desperate, she suggested we went to a group for children with additional needs ... So, so we got a different teacher of the deaf ... and she was just as bad, but less vocal. But eventually, she said the same things as, you know, if you learn to sign, if you sign with your deaf child, she'll never learn to read and write, and we'll never pay for her to go to a deaf school, you won't get a statement in (name of County).

Tina

Although this was an extreme example, many other families told us how difficult it was for them to provide feedback on the health and education services they had received.

Finding 3: Many languages were being used with and by the deaf children.

In our sample, 76% of the parents used BSL or some sort of sign language at home, well above the levels used by deaf children at school. Professionals often tried to discourage this, saying it was not needed, but parents found it useful. Their access to learning BSL was very limited and courses expensive. Families used other spoken community languages at home too, often using different languages in different contexts.

I think that they (the nursery) are taking a lead from the teacher of the deaf from what they say and from what they would like to do with Katie. But again for me it's very good that they say one thing, but in reality it's completely different. Like telling them, 'oh you need to keep the hearing aids in more' but I think they need to... I don't want to give them more work but it would be nice if they had better knowledge and they used some signs as well..

Leanne

It was like entering a whole new world. ... Like, you know, it was really, it was difficult, it's still difficult, you know, because but signing, we've, we've had a few classes and that but it doesn't seem to be that much out there, you know, really. I mean we've applied for college and they've wrote back saying that cos the night course two nights a week and they've said the waiting list is too long, you're gonna have to wait. Now we, we need it. We're not, we're doing it to learn for the sake of learning, we need it and they, so (name of teacher of deaf children) she's trying to contact them and see if she can...but I mean they said no. We was in a sign group but that stopped ... So now it's basically we're trying to learn ourselves, ain't we, with books and YouTube and internet. So it's, it's, it is difficult, you know.

Dave

Finding 4: Support from voluntary organisations for these families could be improved.

NDCS was effective at supporting these families in claiming Disabled Living Allowance, but could have done more after that to support families on a low income in other ways. Existing NDCS activities were sometimes inaccessible or off-putting, for example if the parent on a low income was much younger or from a different cultural background, or if the events were expensive to travel to.

I went tae a family weekend wi' the NDCS in (name of city). I went there one time but...I felt awkward in the place cause everybody was ... They were like ... I say big mums [laughs], and they were married and they, oh and I dinnae feel like I could really speak about, like I dunno, I just...

Louise

Policy implications and recommendations

Recommendation 1: Local Authorities and Health Authorities could use a much wider range of approaches to providing support and information to low-income families. This could include employing early years support staff with first-hand experience of living on a low income, the use of video play sessions and feedback, and information being available more widely in spoken community languages as well as BSL. Telephone or Skype peer support to other families may be a useful service for parents who can't get out easily. Information from other parents is crucial for building up knowledge of deafness and the education system.

Recommendation 2: Local Authorities and Health Authorities should communicate much more clearly to parents what the 1, 3 and 6 month benchmarks are and why they are important. Examples from the Colorado voluntary group *Hands and Voices* show that this crucial information can be presented clearly and visually (bit.ly/2HjwnHp). Furthermore, if information on achieving these benchmarks for babies deaf from birth were provided for each LA and Health Authority, then parents would have a way of evaluating their local services. It might then be easier for the families to recognise when they had received what is regarded as a good level of service, and when they had not.

Recommendation 3: Governments and Local Authorities could do much more to provide free BSL courses for parents available in the home, online and throughout their deaf children's preschool and school years, as in Norway, Ireland and Colorado (Haualand & Holmström, 2019; Department for Education and Skills, Ireland, 2019; Yoshinaga-Itano, Sedey, Wiggin & Chung, 2017). BSL is extremely expensive to learn, and the courses aimed at parents of deaf children are far too short to learn the language thoroughly.

Recommendation 4: Voluntary and third sector organisations could investigate new ways of supporting families on a low income, such as buddying, providing SMS support with internet links, and putting on events accessible to parents who do not read or speak English well. This could include voice files of information in community languages, because generally we found parents with little spoken English were also not literate in their home language.

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A great deal of Yoshinaga-Itano's work is freely available on ResearchGate:
<https://bit.ly/2Y0YAI1>

Project details

Project Name	Telling it like it is: families living on a low income with deaf children
Principal Investigator	Rachel O'Neill, University of Edinburgh, Edinburgh, UK rachel.oneill@ed.ac.uk
Website	http://www.ssc.education.ed.ac.uk/research/tellingit/
Full report	http://www.ssc.education.ed.ac.uk/research/tellingit/tellingit_final.pdf
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